

# Cancer Patient Experience Survey 2015

## Results for North of Scotland Cancer Network (NOSCAN)



June 2016, Official Statistics

# Contents

	<b>Page</b>
<b>Introduction</b>	<b>3</b>
<b>Chapter 1. Overall Results for NOSCAN</b>	<b>4</b>
<b>Chapter 2. Variation in Regional Cancer Network Results across Scotland</b>	<b>21</b>
<b>Chapter 3. Results by Tumour Group for NOSCAN</b>	<b>31</b>
<b>Chapter 4. Condition / Demographic Questions for NOSCAN</b>	<b>51</b>
<b>Appendix A: Mapping of Response Options to Positive, Neutral and Negative Categories</b>	<b>55</b>

# Introduction

This report gives a summary of the results of the NHS Scotland Cancer Patient Experience Survey 2015 for patients who were treated within the North of Scotland Cancer Network (NOSCAN).

Survey questionnaires were sent out in October 2015 to 1,863 patients who were diagnosed with cancer between 1st July 2013 and 31st March 2014 and who received cancer treatment and care within NOSCAN between 1st January 2014 and 30th September 2014.

The survey asked questions about people's experiences of diagnosis, treatment, support, operations, in / outpatient care and home care / support. You can find a full copy of the survey at:

[www.gov.scot/cancersurvey](http://www.gov.scot/cancersurvey)

1,225 NOSCAN patients (66%) returned feedback on their experiences. Of those patients willing to provide information about themselves:

- 48% were male and 52% were female.
- 0% were aged 16 - 25; 1% were aged 26 - 35; 10% were aged 36 - 50; 34% were aged 51 - 65; 35% were aged 66 - 75 and 19% were aged 76 and over.
- 53% did not have any limiting illness or disability.

The survey was commissioned by the Scottish Government as part of the Scottish Care Experience Survey Programme, which aims to use the public's experiences of health and care services to improve those services. The survey was jointly funded by Macmillan Cancer Support and the Scottish Government and was managed by the Scottish Government in partnership with Macmillan Cancer Support and ISD Scotland (part of NHS National Services Scotland). The survey fieldwork was carried out by Quality Health Ltd.

The results of the survey will be used by NOSCAN and the Scottish Government to improve the quality of cancer care in Scotland by focusing on the areas that patients tell us are important to them and where they consider improvements could be made.

Please note that many of the patients who responded to the survey will have had contact with a variety of treatment centres / hospitals during their cancer journey, therefore some of their experiences may relate to treatment or care that took place outside of NOSCAN. Please also note that results for questions 1 - 3 (seeing your GP), 55 - 56 and 58 (home care and support) are based on responses from patients who were resident within the NOSCAN area at the time of their cancer diagnosis / treatment. This differs from the other results in this report, which are based on responses from patients who received their hospital treatment within this regional cancer network.

National results for this survey and further details of the methods used to generate this report are available at:

[www.gov.scot/cancersurvey](http://www.gov.scot/cancersurvey)

# Chapter 1. Overall Results for NOSCAN

The tables / charts in this chapter show how patients treated within this regional cancer network responded to questions about their cancer care. Results for this network are shown alongside the results for NHS Scotland as a whole.

Two types of table / chart are shown in this chapter:

- (a) The first type of table / chart shows how positively or negatively patients responded to questions. For each question, the percentages of positive, neutral / mixed and negative responses are shown. Please see Appendix A for a full breakdown of how patients' responses were grouped into the positive, neutral / mixed or negative categories.
- (b) The second type of table / chart reports the percentage of respondents who selected a particular response in relation to a question. These types of questions are designed to gather background information about respondents (for example, how often a patient visited his / her GP prior to attending hospital for cancer care).

## Notes on Interpretation

**Number of responses** - the number of patients treated within this network who provided a valid response to the question. Note that respondents who indicated that a question was not relevant, or who did not know the answer, are not included in these results. Where a result to a question does not appear within this section it has been suppressed due to the low number of valid responses (fewer than 20).

**Response (%)** - the percentage of positive, neutral / mixed and negative responses received for the question from patients treated within this network. For example, when asked how he / she felt about the length of time he / she had to wait for an appointment, the percentage positive refers to patients who felt they were seen as soon as necessary. Where patients said they should have been seen a lot sooner these responses have been counted as negative. Where patients said they should have been seen a bit sooner their responses have been counted as neutral / mixed. The coloured bars illustrate the percentage positive as green and the percentage negative as red. Where answers were neither positive nor negative (neutral / mixed) the percentage is shown in yellow. Note that results have been rounded to the nearest whole percentage and this occasionally results in the sum of positive, neutral and negative percentages not adding up to exactly 100%.

**% Positive** - the percent positive result; the total percentage of patients treated within this network who responded positively to the question.

**Difference from NHS Scotland** - the difference between this network's percent positive result and the equivalent result for NHS Scotland (for example, -2 means that the result for this network is two percentage points lower than for NHS Scotland as a whole).

**S** Indicates a statistically significant difference in the percent positive result between this network and NHS Scotland as a whole.

**NT** Indicates that a significance test was not carried out because fewer than five respondents within this network selected a positive response or because fewer than five respondents within this network selected a negative / neutral response.

**Median rating** - the "average" rating that respondents gave their overall care within this network. Patients were asked to rate their care on a scale between 0 (Very poor) and 10 (Very good). To calculate the median, ratings from all respondents are listed in numerical order; the median rating is the middle value within that list, with half the ratings placed equal to or above the median and half placed equal to or below the median. The higher the median, the more positive the "average" rating.

**(%) Network** - Percentage of respondents treated within this network who selected this particular response option.

**(%) NHS Scotland** - Percentage of respondents treated within NHS Scotland who selected this particular response option.

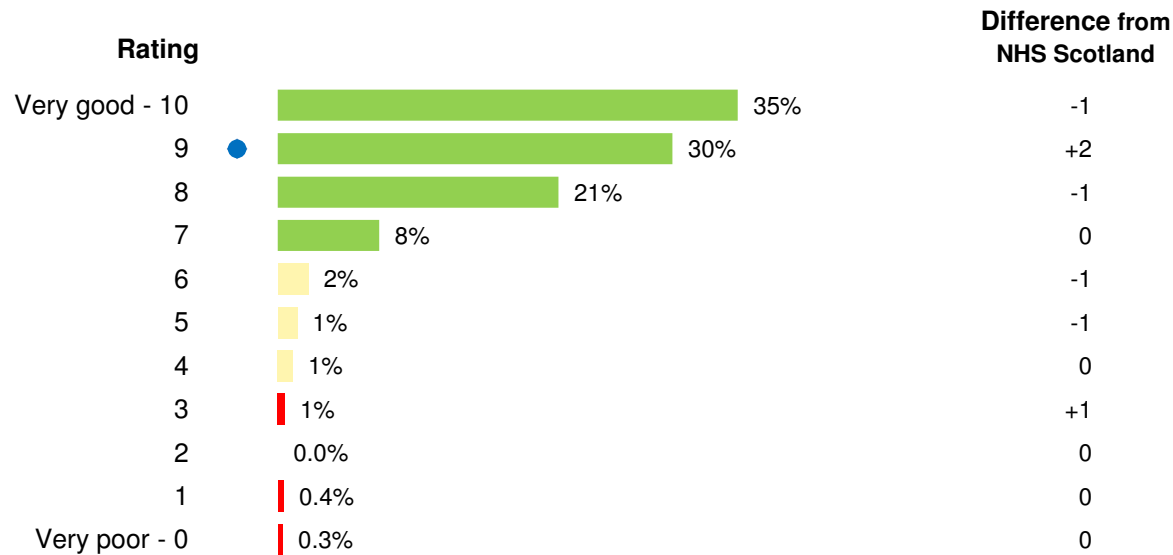
**- -** Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

# 1.1 Overall Care

Patients were asked to rate their overall care on a scale between 0 (Very poor) and 10 (Very good). Ratings of 7 - 10 have been categorised as positive; ratings of 4 - 6 have been categorised as neutral / mixed; ratings of 0 - 3 have been categorised as negative.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
64. Overall, how would you rate your care?	1,169	94	5	94	0	

A full breakdown showing the percentage of respondents who selected each rating within this network is shown below along with the difference from the NHS Scotland result. The median rating given by respondents treated within this network is denoted by the blue dot (●).



Difference from NHS Scotland Median (●): 0.0

## 1.2 Seeing your GP

**Note:** Questions 1 - 3 relate to GP or community-based care. As such, results for these questions are based on responses from patients who were **resident within this network area** at the time of their cancer diagnosis. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment within this network**. Responses from patients who were diagnosed at non-NHS Scotland facilities have been excluded.

1.		(%) Network	(%) NHS Scotland
	None – I went straight to hospital	9	9
	None – I went to hospital following a cancer screening appointment	15	15
	I saw my GP once	42	43
	I saw my GP twice	16	16
	I saw my GP 3 or 4 times	11	10
	I saw my GP 5 or more times	7	7

(Number of responses within this network = 1,157).

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
2.	1,201	81	13	7	81	-1

3.		(%) Network	(%) NHS Scotland
	Less than 3 months	82	83
	3 - 6 months	12	11
	6 - 12 months	3	3
	More than 12 months	3	3

(Number of responses within this network = 1,125).

## 1.3 Diagnostic tests

4. Have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?	(%) Network	(%) NHS Scotland
Yes <sup>1</sup>	97	96
No	3	4

(Number of responses within this network = 1,215).

<sup>1</sup> Of the respondents who had a diagnostic test(s), 80% indicated that the test(s) took place at a hospital within this network. The results for questions 5 - 7 below only include responses from those patients who said that their test(s) took place within this network.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
5. Beforehand, did you have all the information you needed about your test?	885	92	8	92	0	
6. Overall, how did you feel about the length of time you had to wait for your test to be done?	924	84	12	4	84	-1
7. Were the results of the test explained in a way you could understand?	932	81	18		81	0

## 1.4 Finding out what was wrong with you

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
9. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	958	72		28	72	0
10. How do you feel about the way you were told you had cancer?	1,184	88	8	4	88	+2
11. Did you understand the explanation of what was wrong with you?	1,206	76	22		76	+1
12. When you were told you had cancer, were you given written information about the type of cancer you had?	986	64		36	64	+4 <sup>s</sup>



## 1.5 Deciding the best treatment for you

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
13. Before your cancer treatment started, were your treatment options explained to you?	1,021	86	12	0	86	0
14. Were the possible side effects of treatment(s) explained in a way you could understand?	1,126	71	24	5	71	0
15. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	1,112	65	26	9	65	+1
16. Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	1,048	54	28	18	54	+1
17. Were you involved as much as you wanted to be in decisions about your care and treatment?	1,145	78	18	4	78	0

## 1.6 Clinical Nurse Specialist

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
18. Were you given the name of a Clinical Nurse Specialist who would support you through your treatment? <sup>1</sup>	1,134	82		18	82	-2
19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	823	90	6	4	90	0
20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	780	91	8		91	+1

<sup>1</sup> The results for questions 19 - 20 only include responses from patients who said that they were given the name of a Clinical Nurse Specialist.

## 1.7 Support for people with cancer

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
21. Did hospital staff give you information about support or self-help groups for people with cancer?	876	82		18	82	+3
22. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	743	80		20	80	+3
23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	502	44		56	44	-7 <sup>s</sup>

# 1.8 Operations

24. Have you had an operation (such as removal of a tumour or lump) for your cancer?	(%) Network	(%) NHS Scotland
Yes <sup>1</sup>	75	77
No	25	23

(Number of responses within this network = 1,214).

<sup>1</sup> Of the respondents who had an operation, 86% indicated that the operation took place at a hospital within this network. The results for questions 25 - 26 below only include responses from those patients who said that their operation took place within this network.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
25. Beforehand, did you have all the information you needed about your operation?	751	95	5	95	+2 <sup>s</sup>	
26. After the operation, did a member of staff explain how it had gone in a way you could understand?	774	82	16	82	+2	

## 1.9 Hospital care as an inpatient

28. Have you had an operation or stayed overnight for cancer care?	(%) Network	(%) NHS Scotland
Yes <sup>1</sup>	82	83
No	18	17

(Number of responses within this network = 1,211).

<sup>1</sup> Of the respondents who had an operation / stayed overnight, 88% indicated that the operation / stay took place at a hospital within this network. The results for questions 29 - 40 below only include responses from those patients who said that their operation / stay took place within this network.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
29. Did groups of doctors and nurses talk in front of you as if you weren't there?	860	80	16	4	80	-1
30. Did you have confidence and trust in the doctors treating you?	862	86	14		86	0
31. If your family or someone else close to you wanted to talk to a doctor, were they able to?	671	73	22	4	73	-2
32. Did you have confidence and trust in the ward nurses treating you?	867	78	21		78	+1
33. In your opinion, were there enough nurses on duty to care for you in hospital?	862	73	21	6	73	+1
34. While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	859	67	21	12	67	+2
35. Were you given enough privacy when discussing your condition or treatment?	861	79	18	3	79	-3

## 1.9 Hospital care as an inpatient (cont.)

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
36. During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	613	52	32	16	52	+2
37. Do you think the hospital staff did everything they could to help control your pain?	787	88	10	2	88	+1
38. Overall, did you feel you were treated with respect and dignity while you were in hospital?	868	87	12	1	87	0
39. Were you given clear written information about what you should or should not do after leaving hospital?	787	83	17	0	83	+1
40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	816	92	8	0	92	+1

## 1.10 Hospital care as a day patient / outpatient

42. Have you been treated as an outpatient or day case for cancer care?	(%) Network	(%) NHS Scotland
Yes <sup>1</sup>	84	84
No	16	16

(Number of responses within this network = 1,204).

<sup>1</sup> Of the respondents who had been treated as an outpatient or day case, 86% indicated that the treatment / care took place at a hospital within this network. The results for questions 43 - 44 below only include responses from those patients who said that their treatment / care took place within this network.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
43. While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?	679	71	22	7	71	+2
44. The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	829	97			97	-1

## 1.11 Radiotherapy

46. Have you had radiotherapy treatment?	(%) Network	(%) NHS Scotland
Yes <sup>1</sup>	51	49
No	49	51

(Number of responses within this network = 1,184).

<sup>1</sup> Of the respondents who had radiotherapy treatment, 83% indicated that the treatment took place at a hospital within this network. The results for questions 47 - 48 below only include responses from those patients who said that their radiotherapy took place within this network.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
47. Beforehand, did you have all of the information you needed about your radiotherapy treatment?	497	82	15	82	+1	
48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	448	55	29	16	55	+1

## 1.12 Chemotherapy

50. Have you had chemotherapy treatment?	(%) Network	(%) NHS Scotland
Yes <sup>1</sup>	46	48
No	54	52

(Number of responses within this network = 1,178).

<sup>1</sup> Of the respondents who had chemotherapy treatment, 85% indicated that the treatment took place at a hospital within this network. The results for questions 51 - 52 below only include responses from those patients who said that their chemotherapy took place within this network.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
51. Beforehand, did you have all of the information you needed about your chemotherapy treatment?	455	74	22	4	74	-3
52. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	424	59	29	13	59	-3



## 1.13 Home care and support

**Note:** Questions 55, 56 and 58 relate to GP or community-based care. As such, results for these questions are based on responses from patients who were **resident within this network area** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment within this network**.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
54. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	947	56	24	20	56	-1
55. During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	656	54	22	24	54	0
56. Once your cancer treatment finished were you given enough care and support from health or social services (e.g district nurses, home helps or physiotherapists)?	512	48	22	30	48	+3

## 1.14 Care from your General Practice

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
57. As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	992	97	3		97	+1
58. Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	960	72	20	8	72	+2

## 1.15 Your overall NHS Care

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
59. Did the different people treating and caring for you (such as GP, hospital doctors, community nurses) work well together to give you the best possible care?	1,148	91	7		91	+2
60. Have you been given a care plan? This is a document that sets out your needs and goals for caring for your cancer agreed between you and your health professional.	1,052	23	77		23	+1
61. Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes / tests results, etc)?	1,189	89	7	4	89	-1
62. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	1,173	77	17	5	77	+1
63. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	1,135	22	78		22	0

## 1.16 Questions with highest percent positive response

		Number of responses	Response (%)			% Positive	Difference from NHS Scotland
			Positive	Neutral / Mixed	Negative		
44.	The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	829	97			97	-1
57.	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	992	97	3		97	+1
25.	Beforehand, did you have all the information you needed about your operation?	751	95	5		95	+2 <sup>s</sup>
64.	Overall, how would you rate your care?	1,169	94	5		94	0
5.	Beforehand, did you have all the information you needed about your test?	885	92	8		92	0

**Note 1:** Where a question number has been shaded blue, this denotes that the question was also amongst those with the highest percent positive response for NHS Scotland as a whole.

**Note 2:** Some questions in the survey did not have a neutral / mixed response option, therefore respondents only had the opportunity to select either positive or negative response options. Questions that only had positive / negative response options are more likely to be included in the table above than questions that had positive / neutral / negative options. Please see Appendix A for a full breakdown of how responses were grouped into the positive, neutral / mixed and negative categories.

## 1.17 Questions with highest percent negative response

		Number of responses	Response (%)			% Positive	Difference from NHS Scotland
			Positive	Neutral / Mixed	Negative		
63.	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	1,135	22		78	22	0
60.	Have you been given a care plan? This is a document that sets out your needs and goals for caring for your cancer agreed between you and your health professional.	1,052	23		77	23	+1
23.	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	502	44		56	44	-7 <sup>s</sup>
12.	When you were told you had cancer, were you given written information about the type of cancer you had?	986	64		36	64	+4 <sup>s</sup>
56.	Once your cancer treatment finished were you given enough care and support from health or social services (e.g district nurses, home helps or physiotherapists)?	512	48	22	30	48	+3

**Note 1:** Where a question number has been shaded blue, this denotes that the question was also amongst those with the highest percent negative response for NHS Scotland as a whole.

**Note 2:** Some questions in the survey did not have a neutral / mixed response option, therefore respondents only had the opportunity to select either positive or negative response options. Questions that only had positive / negative response options are more likely to be included in the table above than questions that had positive / neutral / negative options. Please see Appendix A for a full breakdown of how responses were grouped into the positive, neutral / mixed and negative categories.

## Chapter 2. Variation in Regional Cancer Network Results across Scotland

The tables / charts in this chapter show this network's percent positive results in relation to the range of percent positive results across all three of the regional cancer networks in Scotland. The percent positive results for NHS Scotland are also shown.

### Notes on Interpretation

■ Range of percent positive results across all regional cancer networks in Scotland - ranges from the lowest network result to the highest network result.

■ This network's percent positive result.

■ NHS Scotland percent positive result (includes results from patients treated at all hospitals in Scotland, not just those within a regional cancer network).

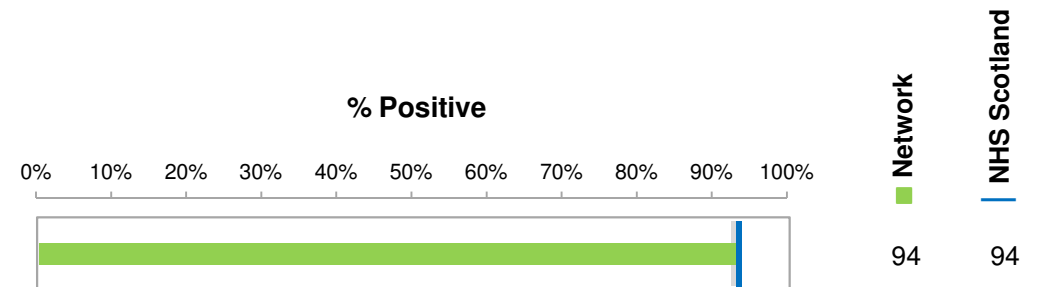
S Indicates a statistically significant difference in the percent positive result between this network and NHS Scotland as a whole.

NT Indicates that a significance test was not carried out because fewer than five respondents within this network selected a positive response or because fewer than five respondents within this network selected a negative / neutral response.

Where a result to a question does not appear within this section it has been suppressed due to the low number of valid responses (fewer than 20).

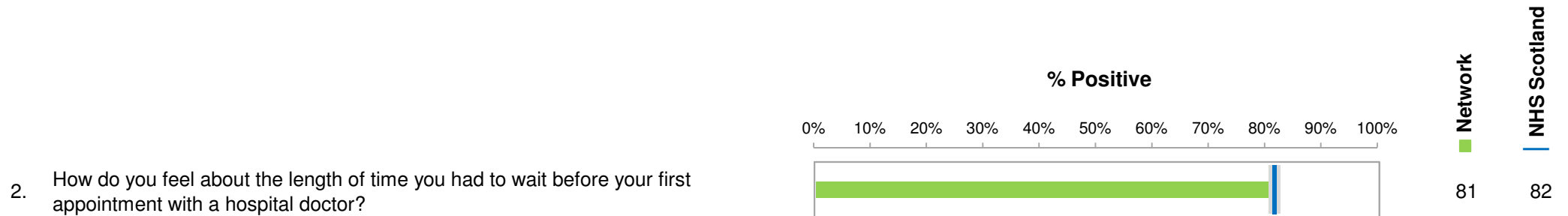
## 2.1 Overall Care

64. Overall, how would you rate your care?

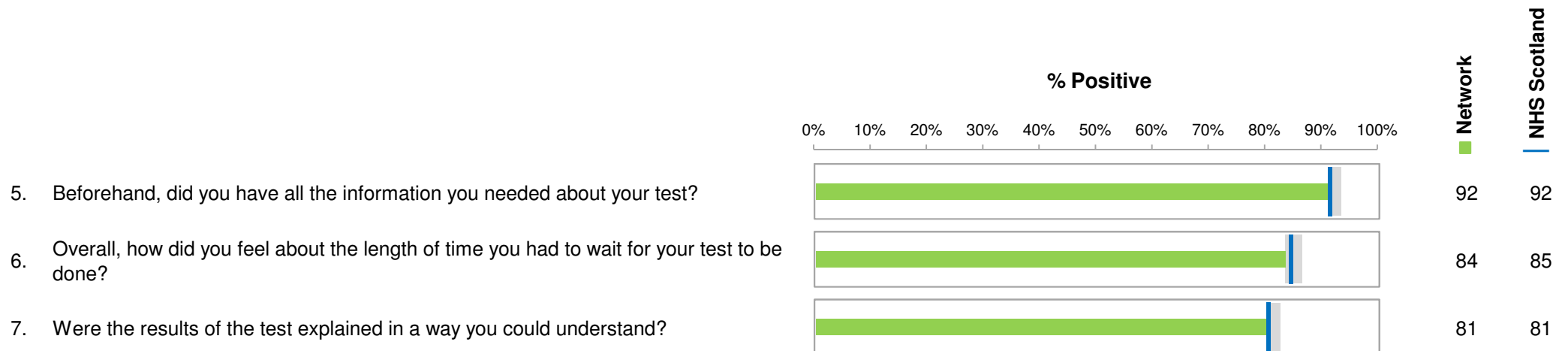


## 2.2 Seeing your GP

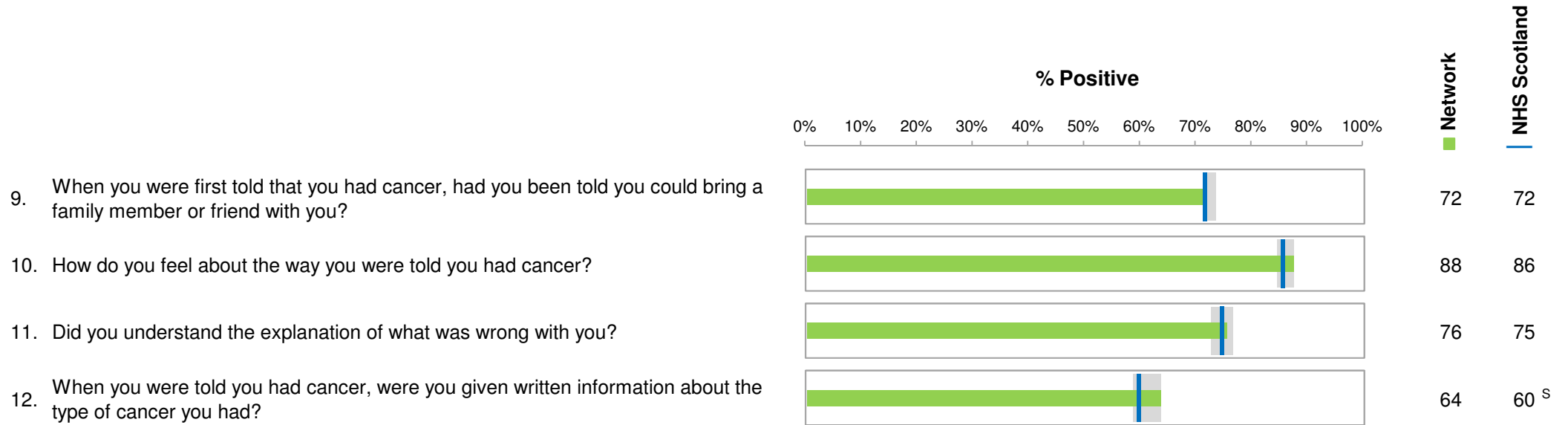
**Note:** Question 2 relates to GP care. As such, the results for this question are based on responses from patients who were **resident within this network area** at the time of their cancer diagnosis. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment within this network**. Responses from patients who were diagnosed at non-NHS Scotland facilities have been excluded.



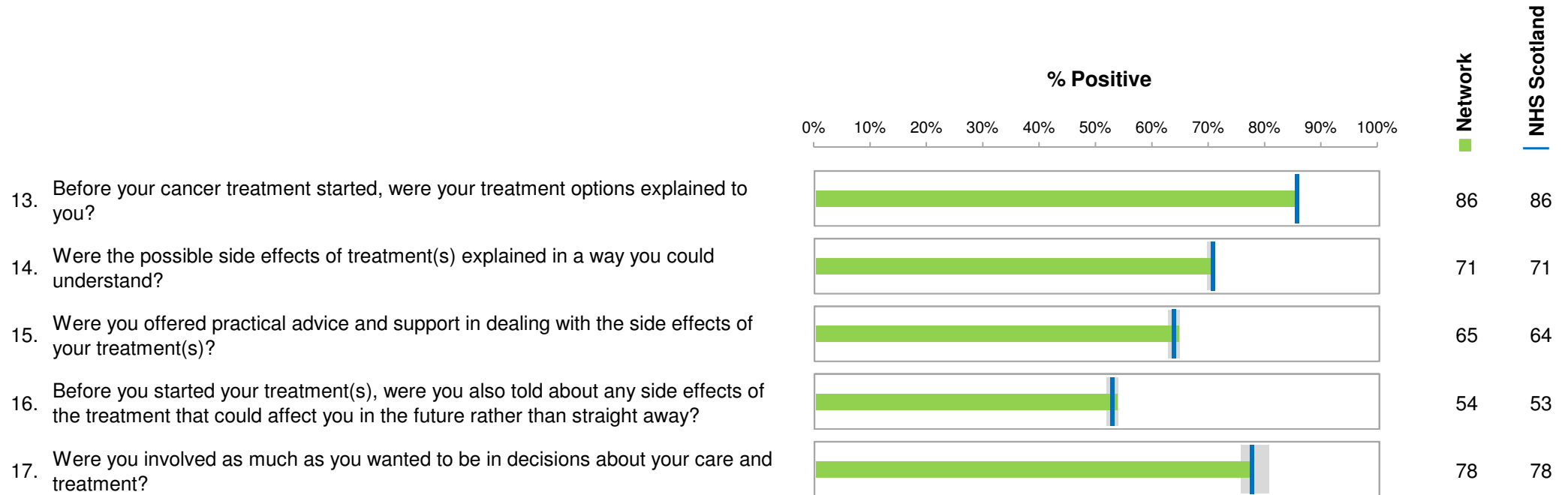
## 2.3 Diagnostic tests



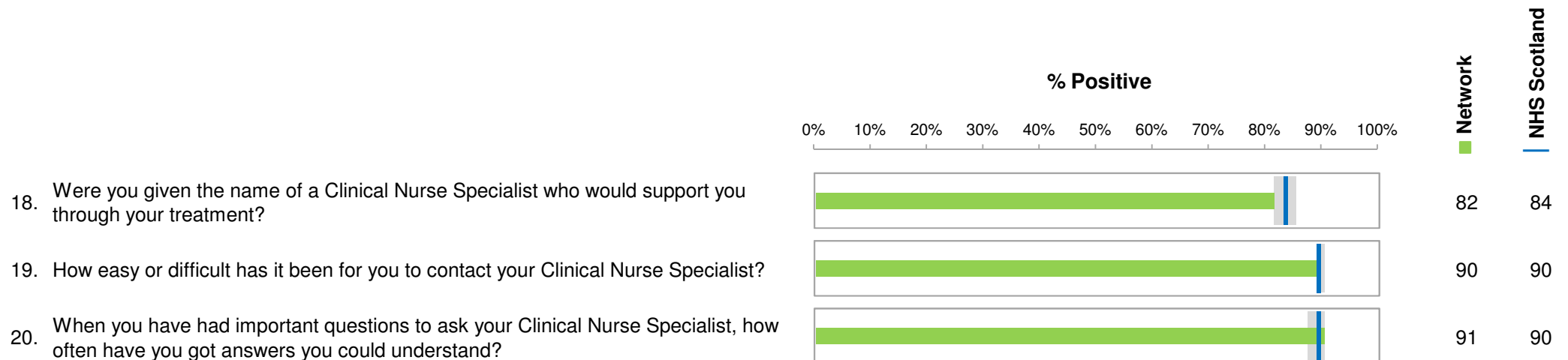
## 2.4 Finding out what was wrong with you



## 2.5 Deciding the best treatment for you

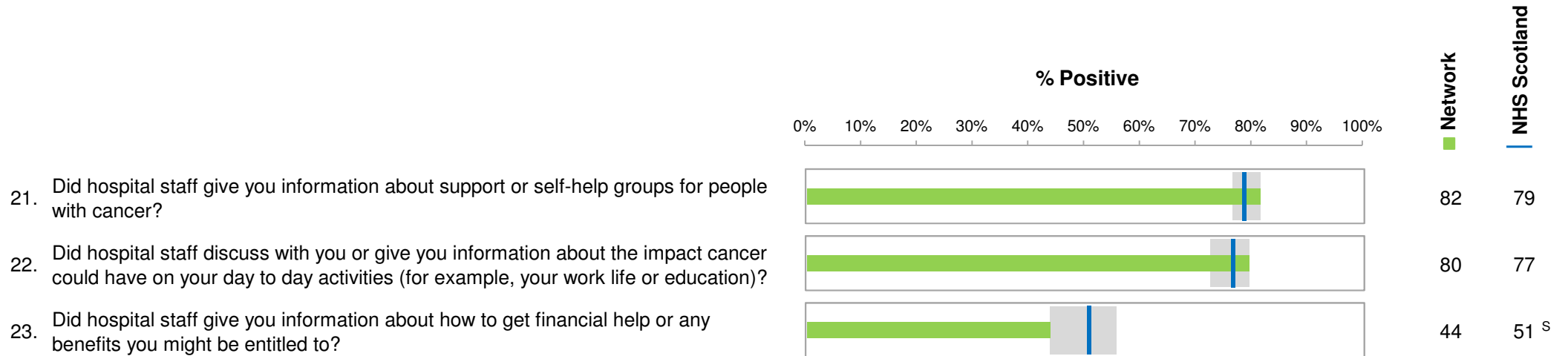


## 2.6 Clinical Nurse Specialist

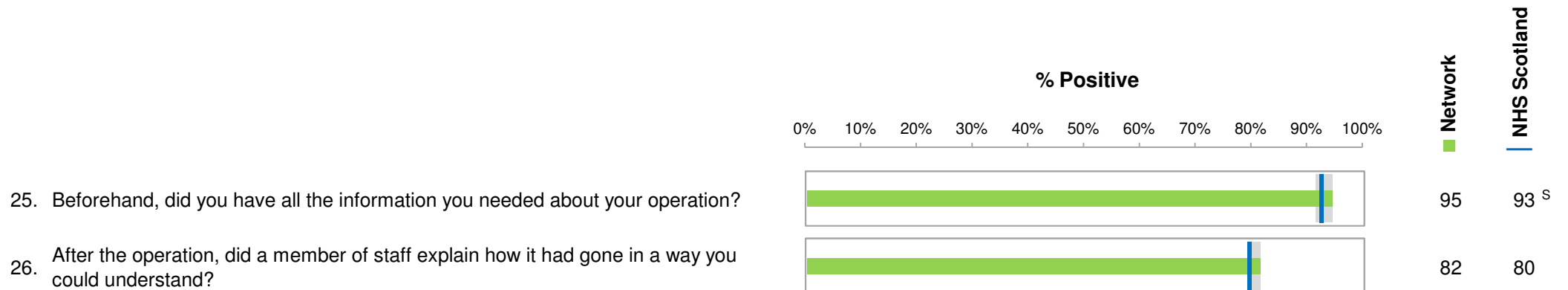




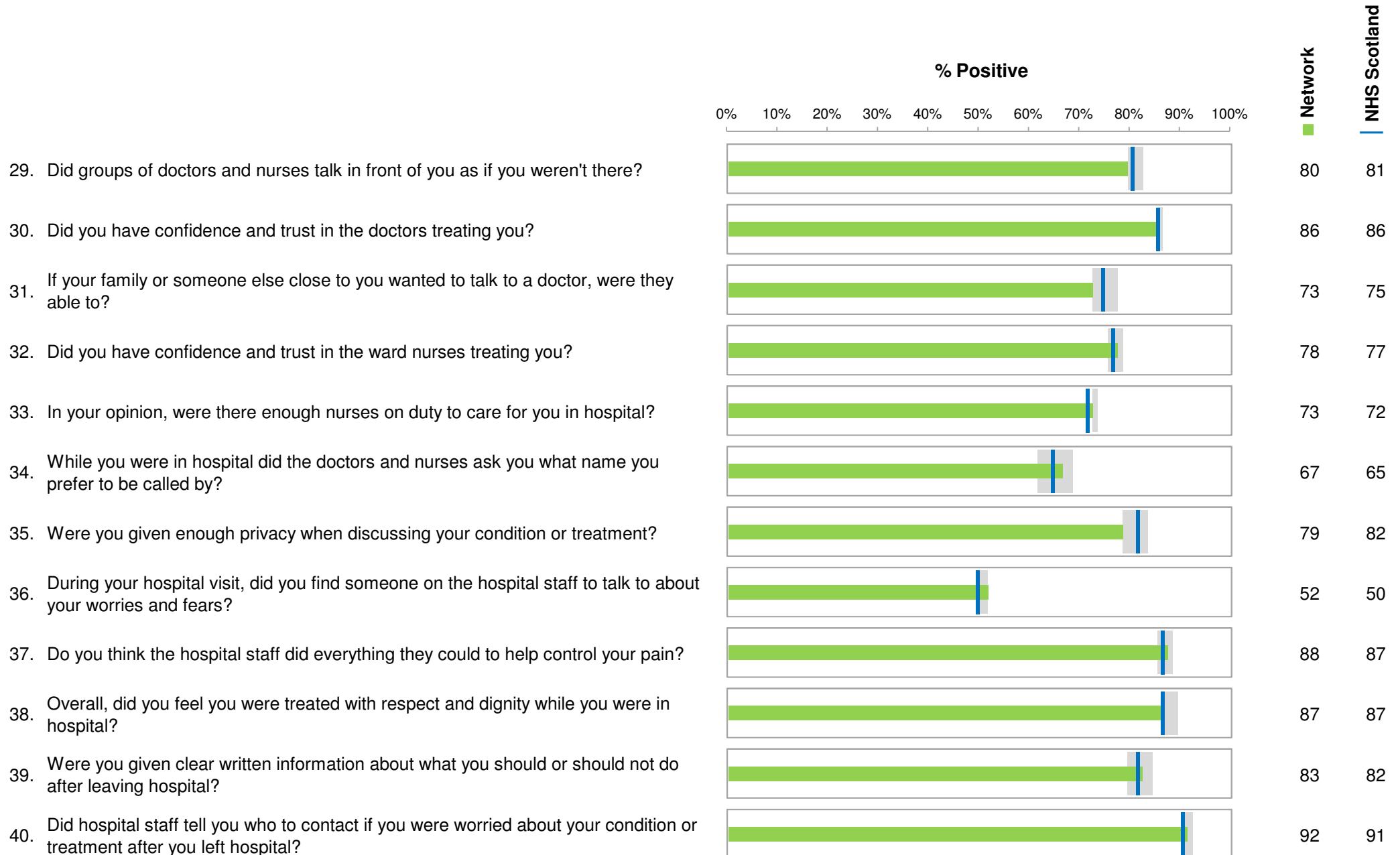
## 2.7 Support for people with cancer



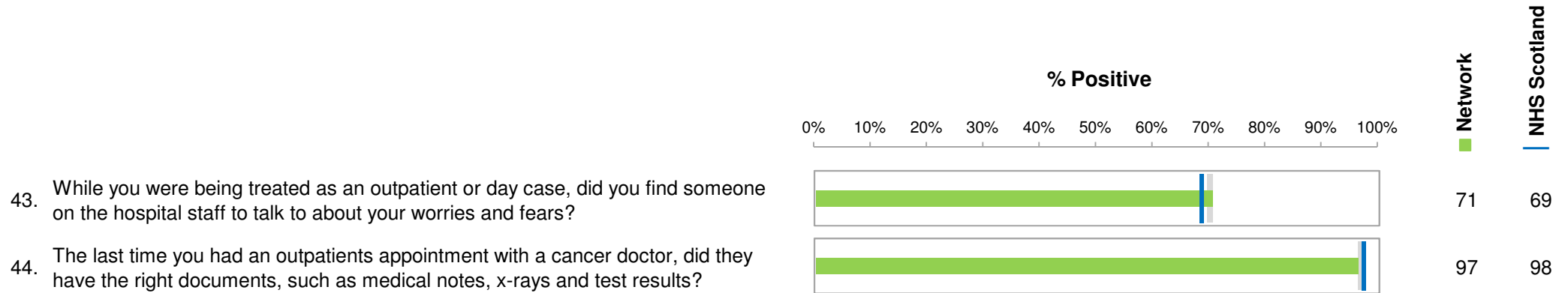
## 2.8 Operations



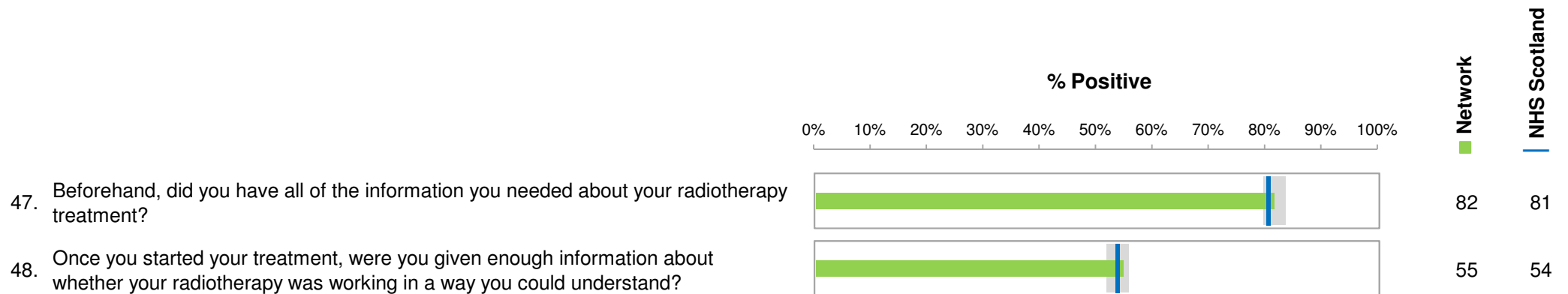
## 2.9 Hospital care as an inpatient



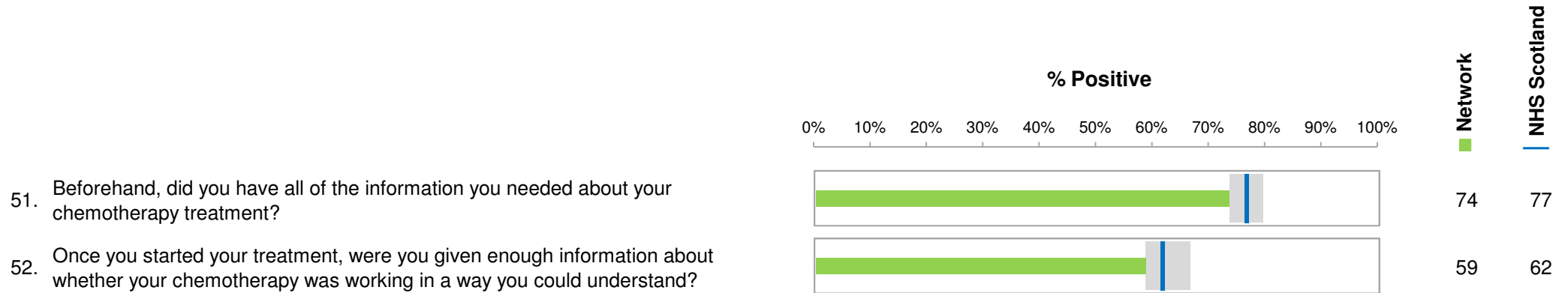
## 2.10 Hospital care as a day patient / outpatient



## 2.11 Radiotherapy

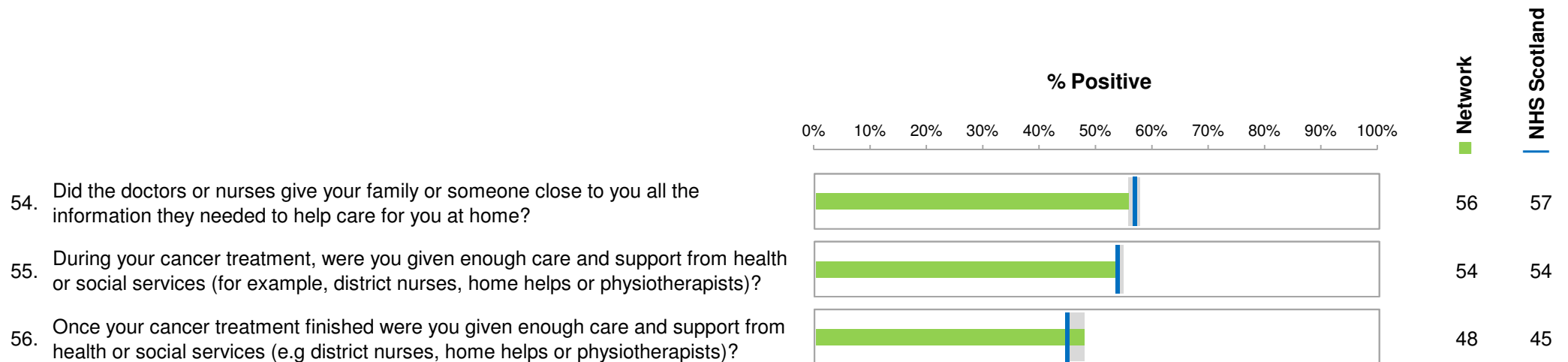


## 2.12 Chemotherapy



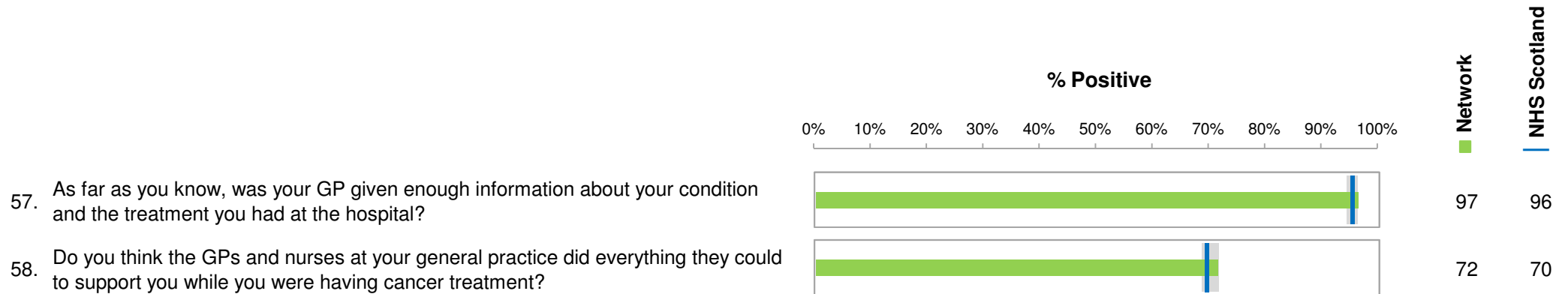
## 2.13 Home care and support

**Note:** Questions 55 and 56 relate to community-based care. As such, results for these questions are based on responses from patients who were **resident within this network area** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment within this network**.

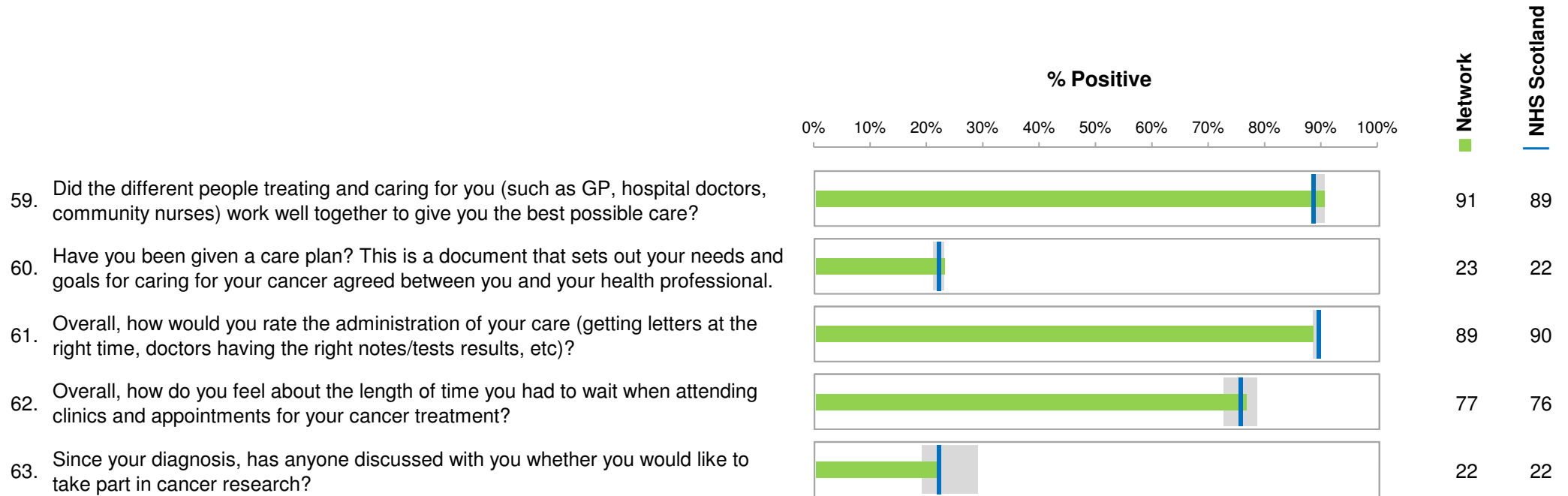


## 2.14 Care from your General Practice

**Note:** Question 58 relates to GP care. As such, results for this question are based on responses from patients who were **resident within this network area** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment within this network**.



## 2.15 Your overall NHS Care



## Chapter 3. Results by Tumour Group for NOSCAN

Survey respondents were allocated to one of 13 tumour groups, based on the type of cancer they were treated for. Where a respondent did not give permission for his / her survey results to be linked to information about his / her cancer type, he / she has been allocated to the "Tumour group unknown" group.

Tumour Group	% of Respondents	
	Network	NHS Scotland
Breast	25	25
Colorectal / Lower Gastrointestinal	16	15
Lung	3	6
Prostate	18	12
Brain / Central Nervous System	0	1
Gynaecological	6	7
Haematological	7	8
Head & Neck	5	5
Sarcoma	1	1
Skin	3	3
Upper Gastrointestinal	3	4
Urological	6	6
Other	0	0
Tumour group unknown	6	7

The tables in this chapter show this network's percent positive results by tumour group. The percent positive results for NHS Scotland are also shown.

### Notes on Interpretation

**Network** - the percent positive result for this network; the total percentage of patients treated within this network who responded positively to the question.

**NHS Scotland** - the percent positive result for NHS Scotland; the total percentage of patients treated within NHS Scotland who responded positively to the question.

- - Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

## 3.1 Overall Care

64. Overall, how would you rate your care?

% Positive

Tumour Group	Network	NHS Scotland
Breast	94	94
Colorectal / Lower Gastrointestinal	93	94
Lung	98	94
Prostate	94	94
Brain / Central Nervous System	--	89
Gynaecological	96	95
Haematological	98	97
Head & Neck	93	93
Sarcoma	--	90
Skin	97	97
Upper Gastrointestinal	92	91
Urological	91	93
Other	--	--
Tumour group unknown	91	89
<b>All Tumour Groups</b>	<b>94</b>	<b>94</b>



## 3.2 Seeing your GP

**Note:** Question 2 relates to GP care. As such, the results for this question are based on responses from patients who were **resident within this network area** at the time of their cancer diagnosis. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment within this network**. Responses from patients who were diagnosed at non-NHS Scotland facilities have been excluded.

2. How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?

**% Positive**

<b>Tumour Group</b>	<b>Network</b>	<b>NHS Scotland</b>
Breast	83	84
Colorectal / Lower Gastrointestinal	78	84
Lung	89	85
Prostate	83	83
Brain / Central Nervous System	--	76
Gynaecological	81	79
Haematological	78	79
Head & Neck	89	84
Sarcoma	--	56
Skin	93	83
Upper Gastrointestinal	70	77
Urological	72	76
Other	--	--
Tumour group unknown	--	85
<b>All Tumour Groups</b>	<b>81</b>	<b>82</b>

## 3.3 Diagnostic tests

Tumour Group	5. Beforehand, did you have all the information you needed about your test?		6. Overall, how did you feel about the length of time you had to wait for your test to be done?		7. Were the results of the test explained in a way you could understand?	
	% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	95	93	90	89	86	84
Colorectal / Lower Gastrointestinal	95	96	84	86	85	84
Lung	92	92	87	87	80	83
Prostate	94	92	81	83	82	80
Brain / Central Nervous System	--	91	--	91	--	77
Gynaecological	90	86	75	77	75	78
Haematological	85	91	80	86	76	81
Head & Neck	85	88	86	87	83	77
Sarcoma	--	82	--	79	--	76
Skin	76	85	90	89	70	76
Upper Gastrointestinal	92	90	72	78	81	77
Urological	86	90	76	80	73	73
Other	--	--	--	--	--	--
Tumour group unknown	97	91	85	84	74	76
<b>All Tumour Groups</b>	<b>92</b>	<b>92</b>	<b>84</b>	<b>85</b>	<b>81</b>	<b>81</b>

## 3.4 Finding out what was wrong with you

9. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?

10. How do you feel about the way you were told you had cancer?

11. Did you understand the explanation of what was wrong with you?

12. When you were told you had cancer, were you given written information about the type of cancer you had?

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
	Breast	72	75	91	89	80	77	67
Colorectal / Lower Gastrointestinal	78	80	86	86	79	82	59	59
Lung	76	75	90	87	76	78	51	54
Prostate	75	77	90	87	82	80	81	78
Brain / Central Nervous System	--	90	--	79	--	77	--	47
Gynaecological	61	57	88	85	71	74	53	54
Haematological	68	72	82	85	56	60	70	70
Head & Neck	70	66	95	88	83	75	58	51
Sarcoma	--	59	--	82	--	62	--	36
Skin	--	55	87	89	72	74	67	74
Upper Gastrointestinal	56	72	78	80	71	72	39	45
Urological	70	63	76	79	69	75	53	51
Other	--	--	--	--	--	--	--	--
Tumour group unknown	79	73	88	85	70	70	51	53
<b>All Tumour Groups</b>	<b>72</b>	<b>72</b>	<b>88</b>	<b>86</b>	<b>76</b>	<b>75</b>	<b>64</b>	<b>60</b>

## 3.5 Deciding the best treatment for you

Tumour Group	13. Before your cancer treatment started, were your treatment options explained to you?		14. Were the possible side effects of treatment(s) explained in a way you could understand?		15. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?		16. Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	
	% Positive		% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	86	85	69	66	67	64	48	46
Colorectal / Lower Gastrointestinal	89	89	74	74	67	68	52	57
Lung	76	87	68	76	61	68	56	59
Prostate	87	86	74	73	72	64	66	62
Brain / Central Nervous System	--	87	--	69	--	49	--	49
Gynaecological	81	85	74	72	59	63	53	52
Haematological	90	89	66	73	66	70	51	58
Head & Neck	93	89	79	69	66	63	52	51
Sarcoma	--	78	--	60	--	59	--	63
Skin	100	86	72	74	68	69	61	62
Upper Gastrointestinal	85	87	63	70	62	67	50	52
Urological	75	82	57	72	46	55	36	50
Other	--	--	--	--	--	--	--	--
Tumour group unknown	86	84	77	67	58	58	59	49
<b>All Tumour Groups</b>	<b>86</b>	<b>86</b>	<b>71</b>	<b>71</b>	<b>65</b>	<b>64</b>	<b>54</b>	<b>53</b>

## 3.5 Deciding the best treatment for you (cont.)

17. Were you involved as much as you wanted to be in decisions about your care and treatment?

**% Positive**

<b>Tumour Group</b>	<b>Network</b>	<b>NHS Scotland</b>
Breast	77	76
Colorectal / Lower Gastrointestinal	78	82
Lung	79	83
Prostate	81	80
Brain / Central Nervous System	--	74
Gynaecological	77	76
Haematological	76	80
Head & Neck	82	77
Sarcoma	--	71
Skin	93	87
Upper Gastrointestinal	73	77
Urological	68	74
Other	--	--
Tumour group unknown	73	70
<b>All Tumour Groups</b>	<b>78</b>	<b>78</b>

## 3.6 Clinical Nurse Specialist

18. Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?

19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?

20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?

Tumour Group	% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	96	95	89	88	90	86
Colorectal / Lower Gastrointestinal	88	90	88	92	91	94
Lung	95	87	97	90	97	91
Prostate	79	81	93	90	94	91
Brain / Central Nervous System	--	84	--	82	--	89
Gynaecological	80	83	90	88	88	90
Haematological	62	70	88	94	95	94
Head & Neck	73	80	97	93	91	93
Sarcoma	--	85	--	96	--	100
Skin	52	78	--	94	--	92
Upper Gastrointestinal	84	81	89	90	81	86
Urological	58	58	97	91	89	88
Other	--	--	--	--	--	--
Tumour group unknown	78	78	84	90	81	84
<b>All Tumour Groups</b>	<b>82</b>	<b>84</b>	<b>90</b>	<b>90</b>	<b>91</b>	<b>90</b>

## 3.7 Support for people with cancer

21. Did hospital staff give you information about support or self-help groups for people with cancer?

22. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?

23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?

Tumour Group	% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	85	83	78	76	39	47
Colorectal / Lower Gastrointestinal	73	78	80	80	45	54
Lung	85	77	87	76	69	61
Prostate	90	85	91	84	43	38
Brain / Central Nervous System	--	77	--	77	--	69
Gynaecological	76	75	80	75	35	58
Haematological	80	84	83	80	52	62
Head & Neck	83	78	76	78	53	58
Sarcoma	--	75	--	--	--	60
Skin	--	88	--	86	--	50
Upper Gastrointestinal	70	76	68	76	--	66
Urological	70	63	59	60	27	32
Other	--	--	--	--	--	--
Tumour group unknown	79	72	74	67	33	45
<b>All Tumour Groups</b>	<b>82</b>	<b>79</b>	<b>80</b>	<b>77</b>	<b>44</b>	<b>51</b>

## 3.8 Operations

25. Beforehand, did you have all the information you needed about your operation?

26. After the operation, did a member of staff explain how it had gone in a way you could understand?

Tumour Group	% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland
Breast	97	93	83	78
Colorectal / Lower Gastrointestinal	97	95	85	85
Lung	--	92	--	84
Prostate	96	94	85	83
Brain / Central Nervous System	--	90	--	75
Gynaecological	91	93	83	81
Haematological	--	89	--	73
Head & Neck	90	91	90	77
Sarcoma	--	93	--	71
Skin	93	90	67	76
Upper Gastrointestinal	86	93	83	81
Urological	88	90	69	78
Other	--	--	--	--
Tumour group unknown	95	90	81	76
<b>All Tumour Groups</b>	<b>95</b>	<b>93</b>	<b>82</b>	<b>80</b>



## 3.9 Hospital care as an inpatient

29. Did groups of doctors and nurses talk in front of you as if you weren't there?

30. Did you have confidence and trust in the doctors treating you?

31. If your family or someone else close to you wanted to talk to a doctor, were they able to?

32. Did you have confidence and trust in the ward nurses treating you?

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	88	87	87	86	74	74	82	79
Colorectal / Lower Gastrointestinal	72	75	85	85	73	75	78	74
Lung	--	78	--	85	--	79	--	83
Prostate	87	81	90	86	79	75	82	79
Brain / Central Nervous System	--	77	--	83	--	57	--	51
Gynaecological	86	86	89	87	64	74	80	76
Haematological	74	82	81	88	73	83	76	81
Head & Neck	82	79	88	89	81	77	82	75
Sarcoma	--	74	--	90	--	73	--	61
Skin	84	86	96	92	--	76	64	81
Upper Gastrointestinal	63	74	77	87	68	80	67	78
Urological	71	76	84	84	67	72	74	74
Other	--	--	--	--	--	--	--	--
Tumour group unknown	77	78	82	83	70	73	67	71
<b>All Tumour Groups</b>	<b>80</b>	<b>81</b>	<b>86</b>	<b>86</b>	<b>73</b>	<b>75</b>	<b>78</b>	<b>77</b>

## 3.9 Hospital care as an inpatient (cont.)

Tumour Group	33. In your opinion, were there enough nurses on duty to care for you in hospital?		34. While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?		35. Were you given enough privacy when discussing your condition or treatment?		36. During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	
	% Positive		% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	74	74	61	55	80	82	53	49
Colorectal / Lower Gastrointestinal	70	69	72	70	79	79	53	52
Lung	--	81	--	80	--	87	--	55
Prostate	73	75	69	67	80	86	66	51
Brain / Central Nervous System	--	63	--	61	--	80	--	40
Gynaecological	72	72	59	62	83	80	43	43
Haematological	72	72	72	69	87	86	43	57
Head & Neck	81	74	67	69	79	84	55	53
Sarcoma	--	68	--	55	--	77	--	39
Skin	76	81	48	62	83	88	--	58
Upper Gastrointestinal	48	61	77	79	63	77	54	52
Urological	71	73	79	72	69	79	45	45
Other	--	--	--	--	--	--	--	--
Tumour group unknown	78	72	67	62	69	75	42	43
<b>All Tumour Groups</b>	<b>73</b>	<b>72</b>	<b>67</b>	<b>65</b>	<b>79</b>	<b>82</b>	<b>52</b>	<b>50</b>

## 3.9 Hospital care as an inpatient (cont.)

37. Do you think the hospital staff did everything they could to help control your pain?

38. Overall, did you feel you were treated with respect and dignity while you were in hospital?

39. Were you given clear written information about what you should or should not do after leaving hospital?

40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	91	88	89	87	91	86	96	95
Colorectal / Lower Gastrointestinal	87	88	87	87	79	79	91	92
Lung	--	87	--	90	--	80	--	88
Prostate	87	88	91	89	89	86	95	92
Brain / Central Nervous System	--	74	--	69	--	67	--	89
Gynaecological	87	86	91	87	85	84	87	88
Haematological	82	89	85	94	74	79	87	93
Head & Neck	85	85	84	85	76	81	84	90
Sarcoma	--	85	--	83	--	58	--	89
Skin	--	81	88	87	82	87	96	94
Upper Gastrointestinal	88	88	80	85	63	78	87	92
Urological	83	83	84	87	76	74	86	81
Other	--	--	--	--	--	--	--	--
Tumour group unknown	88	86	88	87	85	78	98	89
<b>All Tumour Groups</b>	<b>88</b>	<b>87</b>	<b>87</b>	<b>87</b>	<b>83</b>	<b>82</b>	<b>92</b>	<b>91</b>

## 3.10 Hospital care as a day patient / outpatient

43. While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?

44. The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?

Tumour Group	% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland
Breast	71	64	97	97
Colorectal / Lower Gastrointestinal	77	75	93	96
Lung	81	71	100	97
Prostate	83	74	99	99
Brain / Central Nervous System	--	64	--	94
Gynaecological	60	68	95	98
Haematological	57	72	97	98
Head & Neck	71	71	98	99
Sarcoma	--	67	--	96
Skin	--	73	100	97
Upper Gastrointestinal	71	76	100	99
Urological	54	60	98	96
Other	--	--	--	--
Tumour group unknown	59	58	100	98
<b>All Tumour Groups</b>	<b>71</b>	<b>69</b>	<b>97</b>	<b>98</b>

## 3.11 Radiotherapy

47. Beforehand, did you have all of the information you needed about your radiotherapy treatment?

48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?

Tumour Group	% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland
Breast	84	81	53	48
Colorectal / Lower Gastrointestinal	74	80	55	56
Lung	80	85	--	61
Prostate	87	85	59	62
Brain / Central Nervous System	--	88	--	74
Gynaecological	84	82	55	51
Haematological	--	77	--	62
Head & Neck	82	76	59	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	--	79	--	50
Urological	--	77	--	60
Other	--	--	--	--
Tumour group unknown	84	83	64	56
<b>All Tumour Groups</b>	<b>82</b>	<b>81</b>	<b>55</b>	<b>54</b>

## 3.12 Chemotherapy

51. Beforehand, did you have all of the information you needed about your chemotherapy treatment?

52. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?

Tumour Group	% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland
Breast	78	75	50	53
Colorectal / Lower Gastrointestinal	69	77	57	63
Lung	80	82	71	68
Prostate	--	71	--	57
Brain / Central Nervous System	--	82	--	--
Gynaecological	72	72	66	61
Haematological	84	82	73	75
Head & Neck	70	71	68	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	69	80	42	58
Urological	--	80	--	76
Other	--	--	--	--
Tumour group unknown	65	73	58	64
<b>All Tumour Groups</b>	<b>74</b>	<b>77</b>	<b>59</b>	<b>62</b>

## 3.13 Home care and support

**Note:** Questions 55 and 56 relate to community-based care. As such, results for these questions are based on responses from patients who were **resident within this network area** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment within this network**.

Tumour Group	54. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?		55. During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?		56. Once your cancer treatment finished were you given enough care and support from health or social services (e.g district nurses, home helps or physiotherapists)?	
	% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	48	50	48	50	41	37
Colorectal / Lower Gastrointestinal	59	60	61	64	57	55
Lung	72	59	50	52	39	44
Prostate	63	54	55	54	42	45
Brain / Central Nervous System	--	51	--	45	--	--
Gynaecological	50	57	46	41	41	36
Haematological	63	65	48	57	50	48
Head & Neck	55	64	66	64	47	55
Sarcoma	--	44	--	61	--	--
Skin	--	67	--	55	--	58
Upper Gastrointestinal	58	65	68	63	57	55
Urological	55	57	55	54	59	48
Other	--	--	--	--	--	--
Tumour group unknown	53	53	--	42	--	33
<b>All Tumour Groups</b>	<b>56</b>	<b>57</b>	<b>54</b>	<b>54</b>	<b>48</b>	<b>45</b>

## 3.14 Care from your General Practice

**Note:** Question 58 relates to GP care. As such, results for this question are based on responses from patients who were **resident within this network area** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment within this network**.

Tumour Group	57. As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?		58. Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	
	% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland
Breast	98	96	72	70
Colorectal / Lower Gastrointestinal	97	97	78	72
Lung	95	93	77	71
Prostate	97	97	74	72
Brain / Central Nervous System	--	89	--	73
Gynaecological	98	95	67	64
Haematological	97	96	64	66
Head & Neck	90	94	70	69
Sarcoma	--	96	--	71
Skin	96	95	60	74
Upper Gastrointestinal	100	97	75	74
Urological	95	95	70	72
Other	--	--	--	--
Tumour group unknown	91	92	--	67
<b>All Tumour Groups</b>	<b>97</b>	<b>96</b>	<b>72</b>	<b>70</b>



## 3.15 Your overall NHS care

59. Did the different people treating and caring for you (such as GP, hospital doctors, community nurses) work well together to give you the best possible care?

60. Have you been given a care plan? This is a document that sets out your needs and goals for caring for your cancer agreed between you and your health professional.

61. Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc)?

62. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	92	90	27	21	89	91	79	73
Colorectal / Lower Gastrointestinal	92	90	18	22	85	89	76	80
Lung	90	89	29	24	95	92	90	80
Prostate	94	89	26	23	91	88	78	76
Brain / Central Nervous System	--	79	--	18	--	74	--	64
Gynaecological	90	88	17	17	87	88	84	81
Haematological	84	91	25	26	91	94	63	77
Head & Neck	91	90	27	28	90	90	84	77
Sarcoma	--	90	--	20	--	88	--	65
Skin	90	90	21	18	94	94	81	82
Upper Gastrointestinal	87	90	16	20	92	91	68	72
Urological	87	87	13	17	86	85	81	71
Other	--	--	--	--	--	--	--	--
Tumour group unknown	84	87	24	24	91	85	69	72
<b>All Tumour Groups</b>	<b>91</b>	<b>89</b>	<b>23</b>	<b>22</b>	<b>89</b>	<b>90</b>	<b>77</b>	<b>76</b>

## 3.15 Your overall NHS care (cont.)

63. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?

**% Positive**

<b>Tumour Group</b>	<b>Network</b>	<b>NHS Scotland</b>
Breast	28	27
Colorectal / Lower Gastrointestinal	30	30
Lung	35	24
Prostate	14	20
Brain / Central Nervous System	--	25
Gynaecological	6	13
Haematological	33	23
Head & Neck	20	16
Sarcoma	--	26
Skin	13	12
Upper Gastrointestinal	26	25
Urological	10	18
Other	--	--
Tumour group unknown	13	14
<b>All Tumour Groups</b>	<b>22</b>	<b>22</b>

## Chapter 4. Condition / Demographic Questions for NOSCAN

The tables in this chapter show results for condition related / demographic questions. These tables show the percentage of patients within this network who selected each response option when answering these questions. Equivalent results for NHS Scotland are also shown.

### Notes on Interpretation

(%) **Network** - Percentage of respondents treated within this network who selected a particular response option.

(%) **NHS Scotland** - Percentage of respondents treated within NHS Scotland who selected a particular response option.

- - Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

### 4.1 Your condition

	(%) Network	(%) NHS Scotland
65. How long is it since you were first treated for this cancer?		
Less than 1 year	6	6
1 to 5 years	93	93
More than 5 years	1	1

(Number of responses within this network = 1,186).

	(%) Network	(%) NHS Scotland
66. Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?		
Yes	13	14
No <sup>1</sup>	86	85
Does not apply to my type of cancer	1	1

(Number of responses within this network = 1,130).

<sup>1</sup> Respondents who answered "No" were asked to respond to Q67 overleaf.

## 4.1 Your condition (cont.)

67. Which of the following applies?	(%) Network	(%) NHS Scotland
My cancer has been taken out / treated without any sign of further problem	83	81
My cancer was taken out / treated without any sign of further problem, but has since come back / spread to other parts of my body	5	5
None of the above options apply to my type of cancer	12	14

(Number of responses within this network = 913).

## 4.2 About you

68. What was your age on your last birthday?	(%) Network	(%) NHS Scotland
16 - 25	0	0
26 - 35	1	2
36 - 50	10	10
51 - 65	34	34
66 - 75	35	35
76+	19	19

(Number of responses within this network = 1,178).

69. Are you male or female?	(%) Network	(%) NHS Scotland
Male	48	43
Female	52	57

(Number of responses within this network = 1,196).

## 4.2 About you (cont.)

70. Which of the following best describes your sexual orientation?	(%) Network	(%) NHS Scotland
Heterosexual / Straight	99	99
Bisexual	0	0
Gay or Lesbian	0	0
Other	0	0

(Number of responses within this network = 1,158).

71. What is your ethnic group?	(%) Network	(%) NHS Scotland
White	99	99
Mixed or multiple ethnic groups	0	0
Asian, Asian Scottish or Asian British	0	1
African, Caribbean or Black	0	0
Other ethnic group	0	0

(Number of responses within this network = 1,189).

72. What is your main employment status?	(%) Network	(%) NHS Scotland
Work full time	19	17
Work part time	11	10
In full time education or training	0	0
Retired	61	62
Unemployed / looking for work	1	1
Don't work due to illness or disability	6	8
Other	2	2

(Number of responses within this network = 1,204).

## 4.2 About you (cont.)

73. Do you have any of the following? <sup>1</sup>	(%) Network	(%) NHS Scotland
Deafness or severe hearing impairment	16	15
Blindness or severe vision impairment	2	3
A physical disability	10	13
A learning disability	0	1
A mental health condition	4	4
Chronic pain lasting at least 3 months	13	14
Another long - term condition	26	25
None of the above	53	51

(Number of responses within this network = 1,135).

<sup>1</sup> Respondents were asked to "tick all that apply", therefore results may not add up to 100%.

# Appendix A: Mapping of Response Options to Positive, Neutral and Negative Categories

The table below lists the questions that were asked as part of the NHS Scotland Cancer Patient Experience Survey 2015. Where question responses have been coded into positive, neutral / mixed or negative categories, the table indicates which responses have been allocated to each category.

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
1	Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	Information	N/A	N/A	N/A
2	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Pos / Neu / Neg	1: I was seen as soon as I thought was necessary	2: I should have been seen a bit sooner	3: I should have been seen a lot sooner
3	How long was it from the time you first thought something might be wrong with you until you first saw a GP or other doctor?	Information	N/A	N/A	N/A
4	Have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?	Information	N/A	N/A	N/A
5	Beforehand, did you have all the information you needed about your test? (Tick ALL that apply)	Pos / Neu / Neg	1: Yes		2: No, I would have liked more written information 3: No, I would have liked more verbal information 4: Combination of responses 2 & 3
6	Overall, how did you feel about the length of time you had to wait for your test to be done?	Pos / Neu / Neg	1: It was about right	2: It was a little too long	3: It was much too long
7	Were the results of the test explained in a way you could understand?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No, I did not understand the explanation 4: I did not have an explanation but would have liked one
8	Did the test take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A
9	When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Pos / Neu / Neg	1: Yes		2: No
10	How do you feel about the way you were told you had cancer?	Pos / Neu / Neg	1: It was done sensitively	2: It should have been done a bit more sensitively	3: It should have been done a lot more sensitively
11	Did you understand the explanation of what was wrong with you?	Pos / Neu / Neg	1: Yes, I completely understood it	2: Yes, I understood some of it	3: No, I did not understand it

## Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
12	When you were told you had cancer, were you given written information about the type of cancer you had?	Pos / Neu / Neg	1: Yes, and it was easy to understand		2: Yes, but it was difficult to understand 3: No, I was not given written information about the type of cancer I had
13	Before your cancer treatment started, were your treatment options explained to you?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
14	Were the possible side effects of treatment(s) explained in a way you could understand?	Pos / Neu / Neg	1; Yes, definitely	2: Yes, to some extent	3: No, side effects were not explained
15	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No, I was not offered any practical advice or support
16	Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No, future side effects were not explained
17	Were you involved as much as you wanted to be in decisions about your care and treatment?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No, but I would like to have been more involved
18	Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	Pos / Neu / Neg	1: Yes		2: No
19	How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	Pos / Neu / Neg	1: Very easy 2: Quite easy	3: Neither easy nor difficult	4: Quite difficult 5: Very difficult
20	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	Pos / Neu / Neg	1: All or most of the time	2: Some of the time	3: Rarely or never
21	Did hospital staff give you information about support or self-help groups for people with cancer?	Pos / Neu / Neg	1: Yes		2: No, but I would have liked information
22	Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	Pos / Neu / Neg	1: Yes		2: No, but I would have liked a discussion or information
23	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	Pos / Neu / Neg	1: Yes		2: No, but I would have liked information
24	Have you had an operation (such as removal of a tumour or lump) for your cancer?	Information	N/A	N/A	N/A



## Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
25	Beforehand, did you have all the information you needed about your operation? (Tick ALL that apply)	Pos / Neu / Neg	1: Yes		2: No, I would have liked more written information 3: No, I would have liked more verbal information 4: Combination of responses 2 & 3
26	After the operation, did a member of staff explain how it had gone in a way you could understand?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No, but I would have liked an explanation
27	Did the operation take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A
28	Have you had an operation or stayed overnight for cancer care?	Information	N/A	N/A	N/A
29	Did groups of doctors and nurses talk in front of you as if you weren't there?	Pos / Neu / Neg	3: No	2: Yes, sometimes	1: Yes, often
30	Did you have confidence and trust in the doctors treating you?	Pos / Neu / Neg	1: Yes, in all of them	2: Yes, in some of them	3: No, in none of them
31	If your family or someone else close to you wanted to talk to a doctor, were they able to?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
32	Did you have confidence and trust in the ward nurses treating you?	Pos / Neu / Neg	1: Yes, in all of them	2: Yes, in some of them	3: No, in none of them
33	In your opinion, were there enough nurses on duty to care for you in hospital?	Pos / Neu / Neg	1: There were always or nearly always enough on duty	2: There were sometimes enough on duty	3: There were rarely or never enough on duty
34	While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	Pos / Neu / Neg	1: Yes, all of them did	2: Only some of them did	3: None of them did
35	Were you given enough privacy when discussing your condition or treatment?	Pos / Neu / Neg	1: Yes, always	2: Yes, sometimes	3: No
36	During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
37	Do you think the hospital staff did everything they could to help control your pain?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
38	Overall, did you feel you were treated with respect and dignity while you were in hospital?	Pos / Neu / Neg	1: Yes, always	2: Yes, sometimes	3: No
39	Were you given clear written information about what you should or should not do after leaving hospital?	Pos / Neu / Neg	1: Yes		2: No

## Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
40	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Pos / Neu / Neg	1: Yes		2: No
41	Did your overnight stay or operation take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A
42	Have you been treated as an outpatient or day case for cancer care?	Information	N/A	N/A	N/A
43	While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
44	The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	Pos / Neu / Neg	1: Yes		2: No
45	The last time you attended hospital as a day case or outpatient, was this at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A
46	Have you had radiotherapy treatment?	Information	N/A	N/A	N/A
47	Beforehand, did you have all of the information you needed about your radiotherapy treatment?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
48	Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
49	Did your radiotherapy treatment take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A
50	Have you had chemotherapy treatment?	Information	N/A	N/A	N/A
51	Beforehand, did you have all of the information you needed about your chemotherapy treatment?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
52	Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
53	Did your chemotherapy treatment take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A

## Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
54	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
55	During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
56	Once your cancer treatment finished were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
57	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Pos / Neu / Neg	1: Yes		2: No
58	Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No, they could have done more
59	Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	Pos / Neu / Neg	1: Yes, always 2: Yes, most of the time	3: Yes, some of the time	4: No, never
60	Have you been given a care plan? A care plan is a document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional to help meet those goals.	Pos / Neu / Neg	1: Yes		2: No 3: I do not know / understand what a care plan is
61	Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes / tests results, etc)?	Pos / Neu / Neg	1: Very good 2: Good	3: Neither good nor bad	4: Quite bad 5: Very bad
62	Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	Pos / Neu / Neg	3: About right	2: A little too long	1: Much too long
63	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	Pos / Neu / Neg	1: Yes		2: No 3: No, but I would have liked them to
64	Overall, how would you rate your care?	Pos / Neu / Neg	7,8,9,10	4,5,6	0,1,2,3
65	How long is it since you were first treated for this cancer?	Information	N/A	N/A	N/A

## Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
66	Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?	Information	N/A	N/A	N/A
67	Which of the following applies? (Current cancer status)	Information	N/A	N/A	N/A
68	What was your age on your last birthday?	Information	N/A	N/A	N/A
69	Are you male or female?	Information	N/A	N/A	N/A
70	Which of the following best describes your sexual orientation? (Tick ONE box only)	Information	N/A	N/A	N/A
71	What is your ethnic group? (Tick ONE box which best describes your ethnic group)	Information	N/A	N/A	N/A
72	What is your main employment status? (If on maternity or sick leave answer in relation to your usual employment status)	Information	N/A	N/A	N/A
73	Do you have any of the following? Please tick ALL that apply (Disability / Impairment / Condition)	Information	N/A	N/A	N/A

# An Official Statistics Publication for Scotland

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## How to access background or source data

The technical report is available at: [www.gov.scot/cancersurvey](http://www.gov.scot/cancersurvey)

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